Witness Name: Brenda Dibnah
Statement No: WITN1188001
Exhibits: WITN1188002
Dated: 29th May 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF BRENDA DIBNAH

I, Brenda Dibnah will say as follows:-

Section 1. Introduction

1. My name is Brenda Dibnah, I live at GRO-C GRO-C. I was born on GRO-C 1949. I worked as a manager of public houses around the country with my husband, Barry Dibnah. We are now both retired.

2. I make this statement in relation to our son, David George Dibnah (David) who was born on GRO-C 1967 and who sadly died on GRO-C 1995 at the age of 27 having been infected with Human Immunodeficiency Virus (HIV) and Hepatitis C (HCV) and Hepatitis B (HBV) from contaminated blood products. David was our only child.

3. This witness statement has been prepared without the benefit of access to David's medical records.

Section 2. How Affected

4. David had severe Haemophilia A, he was diagnosed at approximately 6 weeks old after he had severe bleeds. When the doctors cut the umbilical cord, David had severe internal bleeding and ended up with gangrene in his stomach. He also lost one of his testicles. When he was operated on it was found that he had Haemophilia.

5. My father had mild Haemophilia but he never informed anyone else in the family so I never knew. Also it appears the condition skipped a generation which is apparently why David had it so severely.

6. The treatment David received as a baby and as a young child was a cold compress and intravenous plasma until he was approximately 7 or 8 years old. After that, he started to have injections of, I believe, cryoprecipitate and then at the age of around 10, the injections changed to Factor VIII.

7. When David was around 11 or 12, he was trained to inject himself with Factor VIII.

8. There was no information or advice provided to us about Factor VIII and any potential risks in taking it. The first time I was aware of HIV in blood products was via the media and TV in the 1980s, by which time it was too late as the damage was already done.

9. As a young child, David mainly attended Hull Royal Infirmary and Kingston General Hospital in Kingston upon Hull; this was where he learned to inject himself with Factor VIII. We moved from Hull to Manchester in 1979 where he attended Manchester Royal Infirmary (MRI) and was under the care of Dr Wensley. Then in approximately 1984 we moved to GRO-C and he attended North Stafford Hospital and was under the care of Dr Ibbetson.

10. It is impossible to say when or by whom David was infected as he received so many injections of Factor VIII from the age of 10 until he died.

11. In about 1984 when David was about 17 years old, he received a letter addressed to him, marked private, asking him to attend the North Stafford Hospital as his blood tests for HIV had come back positive. It was a horrible way for us to be told.

12. Following receipt of the letter we made an appointment with Dr GRO-D I attended the consultation with David and from what I can recall, David was just retold that his tests were positive and that he had HIV. We were told that it did not always lead to AIDS and that he would be closely monitored.

13. We were told nothing else in the meeting. We were given no literature or anything. We were only told that they were working on a cure and there may be medication in due course.

14. Shortly after this we decided to move back to Manchester where David came under the care of again of Dr Wensley and subsequently Dr Charles Hay at the MRI. We felt that there was a better Haematology Department at the MRI and we received a lot more information and help there than anywhere else David had been treated.

15. At MRI David was told how the virus was transmitted and how others could be infected and to take care shaving and similar. We made sure that David had his own towels due to this risk of contaminating others and his Factor VIII treatment was undertaken away from anyone.

16. It was in around 1993/1994, just before David died, that Dr Hay informed David that he had also been infected with HCV and HBV.

Section 3. Other Infections

17. I am not aware of David having any other infections.

Section 4. Consent

18. David was definitely tested without his knowledge and consent. I assume he knew he was being tested just before he received the letter, but only in relation to his Haemophilia.

Section 5. Impact of the Infection

19. Mentally, David seemed to cope quite well after the initial shock and worry following the diagnosis of HIV, it also frightened him. However, David was the type of person to put things to one side and just get on with his life, as he had done with his Haemophilia.

20. David was told that at some point, due to the bleeds caused by Haemophilia, he would not be able to walk and would need a wheelchair. David refused to believe this and just repeated *'no no, just watch this space'*. That is an example of his mindset and how strong willed he was, he was determined to get on with his life.

21. Physically he was okay he did not seem to suffer any symptoms of HIV until he developed Burkitts Lymphoma (Lymphoma) in 1995 as a result of HIV.

22. David was diagnosed with Lymphoma on GRO-C 1995. He only survived 9 weeks after the diagnosis. He died at his family home on GRO-C 1995.

23. At about GRO-C just before David was diagnosed with Lymphoma, he had an operation on his face as he had a lump in neck below his jawbone. Dr Hay said

they would do a biopsy of the lump and then when they opened him up, I was told that it was a mess inside. He had a scar from his ear to his neck, right under his jaw bone. A few weeks later David was diagnosed with Lymphoma.

24. In David's late teens/early 20s, he received HIV treatment in the form of tablets. I cannot remember what tablets, but I remember that it was not the concoction of drugs that most Haemophiliacs who had been infected with HIV received in the mid 1990s. David had no side effects from the treatments.

25. As far as I can recall, David did not receive any treatment for Hepatitis.

26. At the same time that David was diagnosed with Hepatitis, Dr Hay tested me and my husband to make sure we had not been infected. The tests were negative.

27. David had no difficulties or obstacles receiving treatment. As far as I am aware he received the treatment that was available at that time.

28. When David was diagnosed with HIV he was working for a glass manufacturing company. We decided it would be best to tell his boss of the situation but unfortunately this just opened up a can of worms. David's workplace phoned me and said how dare you send a Haemophiliac with HIV to work here. David left immediately and after that we decided not to tell anyone else.

29. David went to work for GRO-C as a trainee off licence manger when we moved to Manchester from GRO-C He then went to college to study computing as he was good with computers. As a result he got a job working for a computer magazine where he would answer readers' questions when they wrote in with their problems. The letters and the answers were published on the 'Help' page of the magazine.

30. David became engaged to a young lady. However, she wanted children so David spoke to the hospital. They said that they could heat treat his sperm but there was no guarantee that any children would not be infected. There was too much pressure on the couple and they spit up in 1994, it was really heartbreaking. I believe that if David had only had Haemophilia, then they would be married and around today. David's illness was just too much for the young couple to deal with.

31. David was able to work until six months before his Lymphoma diagnosis in GRO-C 1995 when he gave up his job which was not long after he split up with his fiancé. He then went to college full time, instead of part time, and was therefore in college when he died.

32. We carried on with our lives as much as we could throughout David's illness. Until David died, we kept the knowledge of his infections secret from everyone except our closest family, such as my brother and my husband's parents. We did this because of the stigma associated with HIV and AIDS.

33. David had a group of friends and they always looked after him, but they only knew of his Haemophilia, and not his HIV or Hepatitis. After David died I told them of his infections because I did not want to hide behind closed doors anymore.

34. We were hurting beyond words and no one could make my hurt less, nor my heart break any further. David was my only child; not only did HIV and Hepatitis take our son's life, it took mine as well. My life and my future all ended when David died. I would have no daughter in law, no grandchildren, no birthdays, no happy Christmases and no memories to grow old with.

35. I was sterilized in the 1960s after David was born as I was told any other children would also have Haemophilia and so I did not take the chance. In the 1980s I had this reversed. I became pregnant in the early 1980s but it was an ectopic pregnancy so David was our only child.

Section 6. Treatment/care/support

36. At MRI we had a Haemophilia coordinator called Meg Openshaw; she was our main support. She was a trained nurse and she was with us when David died. We were introduced to Meg years before David died as she was part of the Haemotology Department in Dr Hay's team. They were exceptionally good, very kind and caring people. We could always go and talk and discuss matters whenever we needed to. Meg came to our house many times, even before David was diagnosed with Lymphoma. She was a big support to us.

37. After David was diagnosed with Lymphoma he was in and out of hospital isolation as they were trying to treat the Lymphoma with chemotherapy and radiotherapy; however he then developed another infection due to the chemotherapy.

38. David was taken back into hospital for treatment for this infection. He was treated with antibiotics but they allowed him home two weeks before he died. We were then offered some respite care at GRO-C was a specialist care home that looks after people infected with HIV and AIDS. We went there for a week and then when we came home, a week later David died.

39. On the Monday before he died, we took him in to see Dr Hay and they took us aside and said it was just a matter of time before David would die so did we want him to stay in hospital or go home. We took him home and Meg came home with us helping us look after him while he was dying. She stayed till he died on the Wednesday.

40. We were involved with Meg for around 4 months. She was our counsellor in a way as we would talk to her every week and we stayed friends for a few years after David died.

Section 7. Financial Assistance

41. I believe it was MRI that told us financial assistance was available.

42. David applied to the MacFarlane Trust and started to receive regular monthly payments. It was through this that he separately qualified for a £40,000 payment, but I cannot remember who from. I think it was some government scheme to do with litigation, as far as I am aware.

43. There were preconditions to receiving this payment however and I think David had to sign a waiver form. I remember hearing something about if everyone did not sign the form, then no one would receive this payment.

44. David was in his early 20s and he wanted to do things himself so we were not too involved with the application process. However it is an insult to put only that much value on someone's life.

45. Quite a while after David died, perhaps around 2009, we did get a payment from the Skipton Fund. The payment was one where we could apply for money through David's estate. We received two ex-gratia payments, one of £20,000 and one of £50,000.

46. The application process was straightforward. We did not know about it until a friend of ours, who has HIV, told us about the Fund and said that it covered people even when the infected person had died. I then rang them and they said we qualified so I was told to fill in the form and then send them David's death certificate.

47. The payments received were an insult. The money was just hush money. No amount of money will bring our boy back; someone should be held accountable for all these deaths. It is not about financial gain but about responsibility. If you murdered someone you would go to jail for life. They murdered 1200/1300 people at least.

Section 8. Other Issues

48. I have no medical records of David. I only have photos, showing him looking good and then the progression to when he was diagnosed with Lymphoma. His face looks distorted and you would not know it was the same person. I have exhibited two photos to this statement at WITN1188002.

49. I certainly feel that the authorities and government knew of the risks involved with importing contaminated blood products and withheld the information about the risks for whatever reason.

50. David was treated with the infected blood products without being given any information regarding the consequences.

51. I need to know who took everything away from me as well as everything from all the other families of Haemophiliacs.

Anonymity, disclosure and redaction

52. I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

53. I do wish to be called to give oral evidence if I can assist the Inquiry.

Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed GRO-C ....

Brenda Dibnah

Dated: 29th May 2019